

A close-up portrait of a young girl with Down syndrome, smiling warmly. She has light brown, wavy hair and is wearing a white t-shirt with colorful letters. The background is a solid, bright yellow.

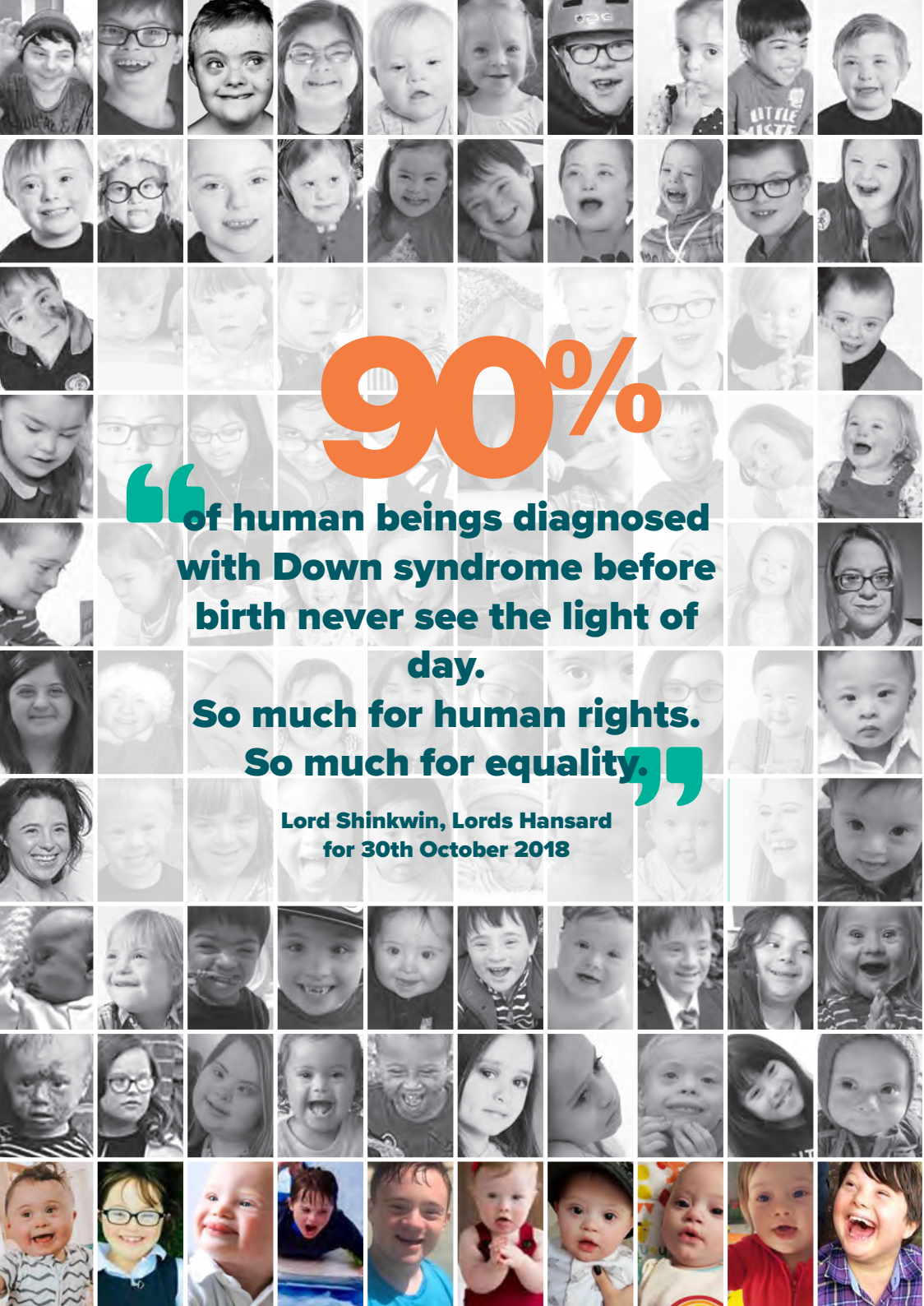
Sharing the news

The maternity experience
of parents of a baby with
Down syndrome



+

Positive about
Down syndrome



90%

“of human beings diagnosed with Down syndrome before birth never see the light of day. So much for human rights. So much for equality.”

Lord Shinkwin, Lords Hansard for 30th October 2018

Positive about Down syndrome provides professionally designed literature to maternity units to ensure new and expectant parents have access to the lived experience of people with Down syndrome.

A website written by parents for parents and parents to be.

Terminology:

Throughout the report, where reference is made to a high chance result, this indicates a likelihood of baby having Down syndrome as greater than 1:150.

Report first published October 2019



Introduction

- A message
- Research
- Remit of screening

Recommendations

- Delivering results
- Support

Down syndrome timeline

Survey methodology

How to share the news

Report findings

- Delivering results
 - Expectation to screen
 - Expectation to terminate
 - Decisions disregarded
 - Sharing the news

Support

Information

Going forward

- Cultural change
- Down syndrome Charter



**I am not
a fetal
abnormality**

I am TOM

A MESSAGE FROM NICOLA ENOCH

Before my son Tom was even born, we'd experienced subliminal and blatant discrimination, which is deemed acceptable by many medical professionals, when considering a baby with Down syndrome. The negative attitudes and language used by medical professionals and society had led me to believe having a baby with Down syndrome was something to be feared and avoided.

We know that **90%** of women who receive a positive antenatal result of baby having Down syndrome go on to terminate. There is much ignorance and fear around Down syndrome and this report is evidence of the medical attitudes, language and expectations that without doubt influence this figure. There needs to be a change in culture to ensure the systemic discrimination this report identifies is addressed and that every expectant and new parent of a baby with Down syndrome is treated with the same respect and care as any other expectant or new parent.

During my lifetime outcomes socially, educationally and medically for people with Down syndrome have improved drastically yet outdated perceptions and opinions permeate many maternity units. It is essential that medical professionals understand and accept that Down syndrome is no longer a life limiting condition; that they see beyond the medical model and realise that people with Down syndrome lead full and rewarding lives and are loved and valued members of their families and communities.

I am forever grateful that the screening when I was pregnant with Tom was not more accurate and am acutely aware that today as screening technology advances, expectant parents are making life/death decisions with inadequate support and care, influenced by outdated perceptions and attitudes which have to be challenged.

Nicola



RESEARCH

Research is a critical element of the puzzle to improving the lives of people with Down syndrome.

When the DSRF was founded over twenty years ago, the scientific community was on the cusp of sequencing the human genome. Now we understand that our environment plays a critical role in the genes we turn off or on. These advances have told us Down syndrome is not simply a 'static' condition and the potential of a person with Down syndrome is not written in stone.

Unfortunately, while research into many conditions has surged ahead, the Down syndrome community has been largely ignored in terms of research funding to promote enhanced outcomes.

The focus of spending has instead been on refining and innovating prenatal screening but

at the expense of the quality of life of people living with Down syndrome. Lack of research into ways to improve potential and quality of life further darken and restrict the horizons presented to new parents in antenatal clinics.

People affected by Down syndrome deserve the same research innovations to improve their health that other conditions have. Yet the annual research spending per person with Down syndrome to improve quality of life is currently in the region of **£16.52**, of which only **£5.33** is towards treatment studies to test interventions. Meanwhile, funding into antenatal screening for Down syndrome between 2010-18 by NIHR and MRC was over **£5.4 million** and the NHS spends in excess of **£30 million** every year on its antenatal screening programme.

Dr Elizabeth Corcoran
DSRF



Antenatal screening for Down syndrome was introduced in the 1970's on the basis that it was preventative and therefore cheaper than the lifetime implications of someone being born with Down syndrome. In order to produce the desired outcome, it may have been deemed necessary to present Down syndrome in a negative light, an approach which has led to stigma, discrimination and misinformation.

Today, we view those with a disability as an integral and valued component of a diverse society, and the health and well-being of minorities is now well protected by legislation and guidance. Antenatal screening is now promoted as being offered to provide women with information about their pregnancy.

REMIT OF SCREENING

However, as this report highlights, accurate contemporary information and understanding about the lived experience is absent, with outdated perceptions and attitudes among many medical professionals, resulting in systemic discrimination.

The inherent inequalities in antenatal screening have to be a consideration of all staff involved in screening programmes and must be addressed. As such, the social model of disability should take on a greater importance than previously afforded and positive awareness should remain uppermost in people's minds.

Lynn Murray
Don't Screen Us Out



Recommendations

To implement a Down syndrome Charter to standardise information around Down syndrome and promote collaboration with local support networks.

The charter will provide the framework to enable new and expectant parents to have a positive maternity experience.

DELIVERING RESULTS

- ▶ Cultural change to address the systemic discrimination prevalent in today's maternity service; an understanding among medical professionals that life with Down syndrome is worth living.
- ▶ Results to be imparted/delivered in a non-directive, non-judgemental and supportive way, with no preeminent option.
- ▶ It should not be assumed that a woman will choose to have a termination.
- ▶ A woman's decision should be accepted and respected.



There was actually very little extra support, and none related specifically to Down syndrome. Staff were positive and kind but often surprised that we were keeping the baby.



She sat us down and told us all the negative things about having a child with Down syndrome and she said, "You're only 28, you're both so young, you should terminate and start again."

SUPPORT

- ▶ Women to have rapid access to appropriate counselling by trained staff when high chance result shared.
- ▶ New parents being advised baby has Down syndrome should be signposted to local and national support organisations.
- ▶ Staff to be trained around the reality of living with Down syndrome in modern Britain.
- ▶ Counselling to contain balanced information about Down syndrome and not focus on what options are available, unless this information is requested.
- ▶ Maternity units to have details of local families/support groups.



On the phone she asked me five times whether I wanted to get it taken care of and those were her words, "taken care of."

INFORMATION

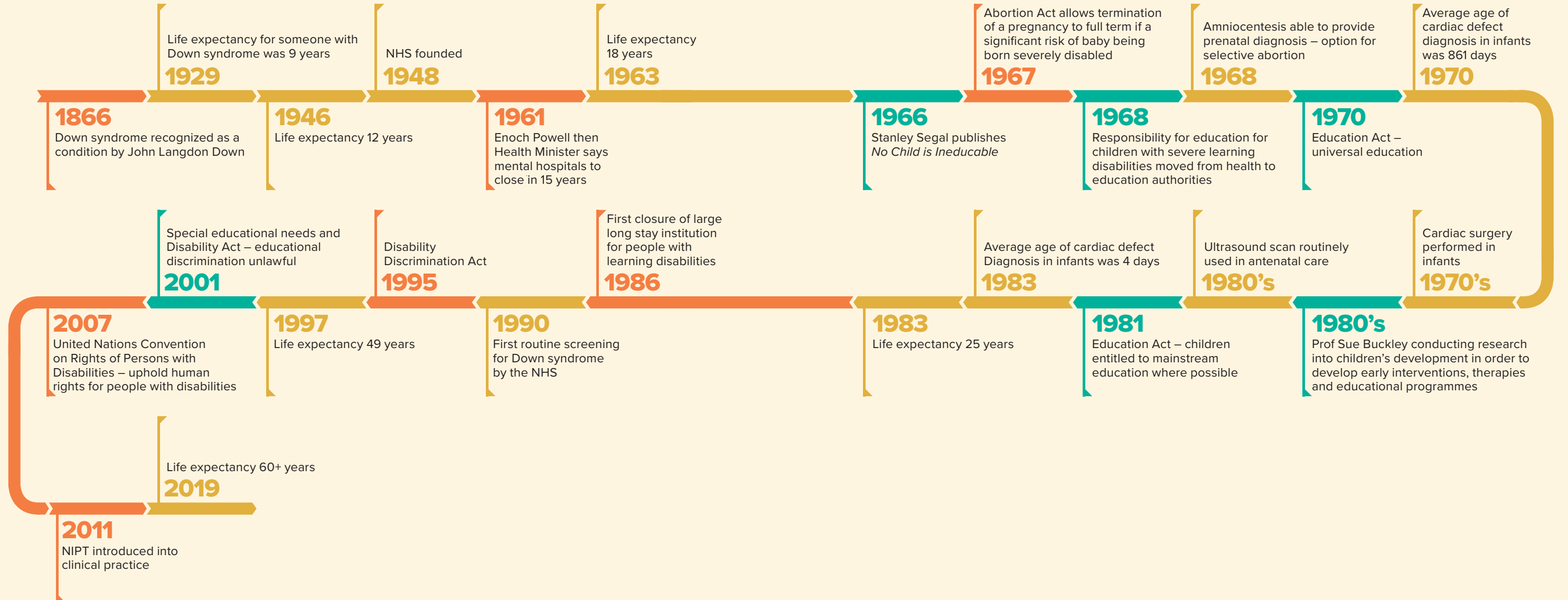


Only info I was given was a booklet by ARC but it only spoke about terminating, nothing about having a baby with Downs which is what I expected and needed. Hospitals need to give both sides not just push mums to terminate.

- ▶ Expectant parents to be provided with information about the reality of living with Down syndrome.
- ▶ Details of local and national support organisations such as PADS and DSA to be provided at time of sharing the news.
- ▶ Many expectant parents find it insulting and disrespectful for termination to be mentioned. Parents should only be referred to information about termination if this is a consideration.

Down syndrome timeline

Education Social Health



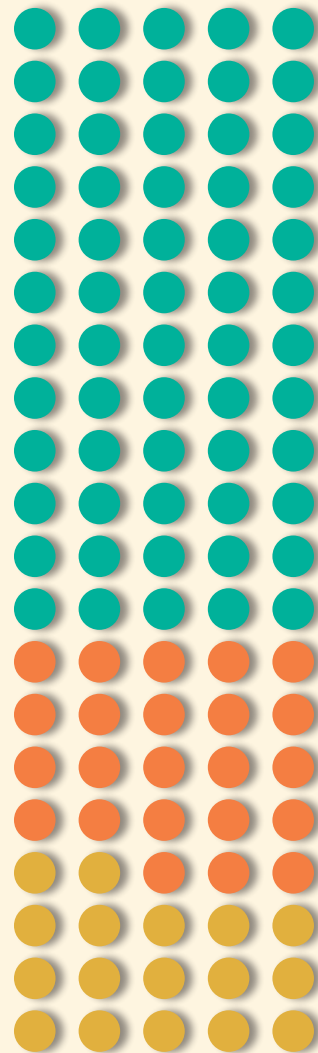


Survey methodology

The aim of the study is to track the maternity experience of women who have had a baby with Down syndrome in the UK since 2000.

The survey was launched in April 2018 and promoted via social media and a network of support groups.

Open to mothers across England, Wales & Scotland, the data was collected via Survey Monkey.



Did you receive a positive antenatal, high chance (and chose no further tests) or postnatal confirmation of baby having Down syndrome?

60%
Postnatal
748 responses

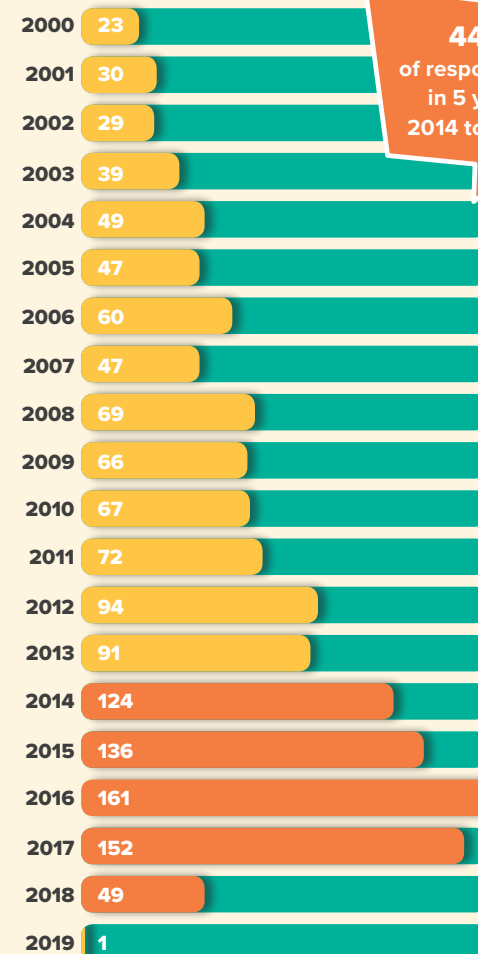
23%
High chance
280 responses

17%
Positive antenatal
214 responses

Based on 1,242 Responses, 168 skipped

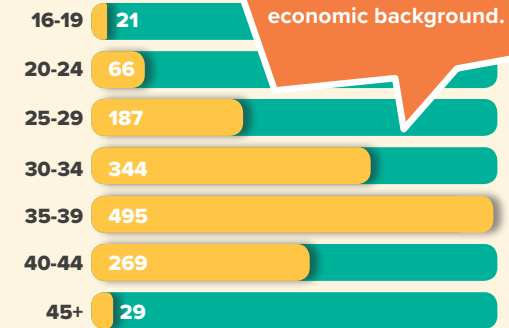
Based on 1406 Responses, 4 skipped

In what year was your baby born?



44%
of respondents
in 5 years
2014 to 2018.

What age were you when your baby was born?



Average age for women to have babies in UK is 28.8 years. This increases by socio economic background.

Based on 1409 Responses, 1 skipped

The survey questions included both multiple choice and free text answers. Questions explored experiences around antenatal screening, including sharing of initial blood-test results and the experience of women who went on to have a diagnostic test, together with those who discovered baby has Down syndrome post birth.

▶ 1410 women completed the questionnaire

How to share the news



Your baby has Down Syndrome. Don't worry though children have been born with Down syndrome since the beginning of time. Down syndrome is a naturally occurring chromosome arrangement that has always been part of the human condition. Your child will be blessed to be a member of an amazing population of people that makes this world a better place to live in.

Something as simple as the language we use could change the perception of how the world views our children. What a wonderful, wonderful world it would be.



**Positive about
Down syndrome**



Report findings

DELIVERING RESULTS

Over the years we have assimilated much anecdotal evidence of women feeling pressured to proceed with antenatal screening, and for those who discovered there was a high chance of baby having Down syndrome, to go on and have a diagnostic test. Many parents have reported an expectation by medical professionals that the purpose of screening was to terminate the pregnancy if it was established baby has Down syndrome. The Sharing the News survey corroborates those anecdotes.

Expectation to screen

Of **1,231** women, **41%** were of the understanding that screening for Down syndrome is a routine element of their antenatal care and did not realise that it is optional. This contradicts NICE guidelines, which clearly state, “a woman should understand that it is their choice to embark on screening for Down syndrome.”



The midwife tried to suggest it was routine and normal to have the tests.



I was told by my midwife that screening was in my best interest.

For those who receive a high chance result from initial blood tests, there is an overwhelming expectation for them to have further tests, with **91%** of **272** women being offered further tests when a high chance result was given.



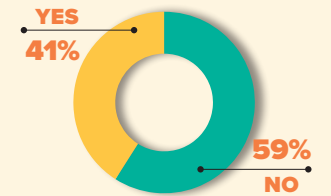
I was told I was being irresponsible by not accepting further tests.



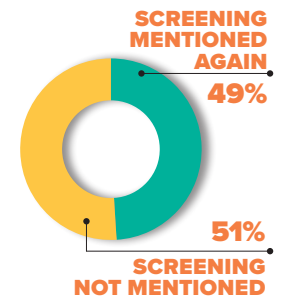
I remember coming away feeling guilty about my decision not to have the test.



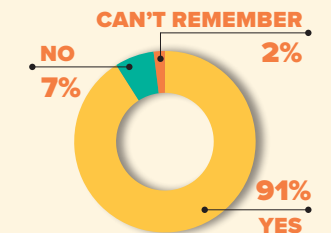
Did you tell professionals you did not want screening/testing for Down syndrome?



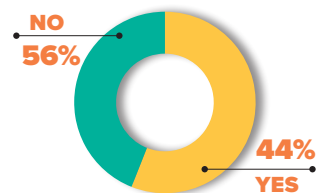
What was general response to your decision not to proceed with screening/testing for Down syndrome?



Were you offered further tests when the high likelihood result was given?



If you declined further tests, did you feel under pressure to have further tests?





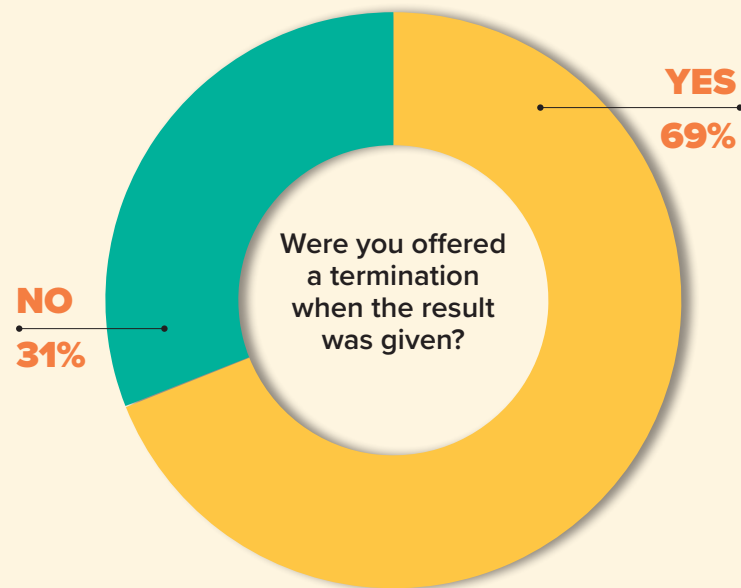
Expectation to terminate

Our data shows an expectation by medical professionals for women to terminate when a baby is identified as having Down syndrome.

Of **208** women who had a diagnostic test, when given the result that baby has Down syndrome, **69%** were offered a termination in the same conversation.

Only one fifth of the expectant mums who had a diagnostic test to confirm baby has Down syndrome were never offered a termination.

It should be remembered that these are women who continued with their pregnancy: we know that **90%** of women who receive a positive result go onto terminate.



She said "Sorry, it's bad news, baby does have Down syndrome; I've booked you in for a termination on Thursday at 10."



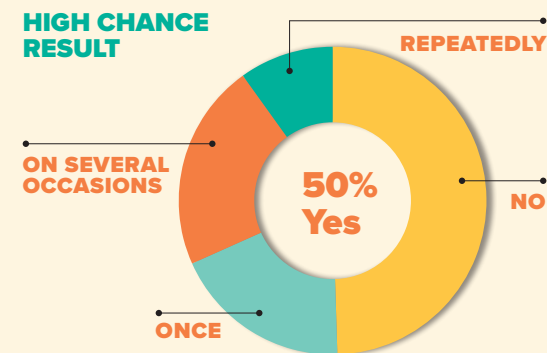
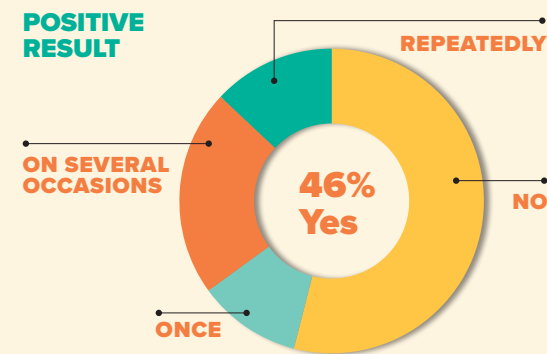
One Dr asked me why I did not terminate; he felt I was selfish.



Every appointment it was mentioned even though I wrote on the front of my notes and highlighted "Termination is not an option" I was asked, "But do you want further testing to help you make that decision?"

Based on 206 Responses, 1204 did not answer (skipped)

Was the option to terminate mentioned after you had advised you were continuing with the pregnancy?



Decisions disregarded

A recurring finding from the survey was how often a woman's decision is being disregarded, her choice undermined throughout her pregnancy experience.

Of **489** women who advised that they did not want screening/testing for Down syndrome, **49%** advised that their decision was not respected, with **34%** having screening mentioned a couple of times, **15%** reported that screening was repeatedly mentioned.

Even after advising that they are continuing with the pregnancy, many women are being subjected to their decision being ignored by repeatedly being offered terminations, through in some instances, to days before birth.

Of **210** women who had received a positive result and advised that they were continuing the pregnancy, termination was still mentioned to **46%** of these expectant mums. Of **271** who had a high chance result, despite saying they were continuing, **50%** were offered terminations.

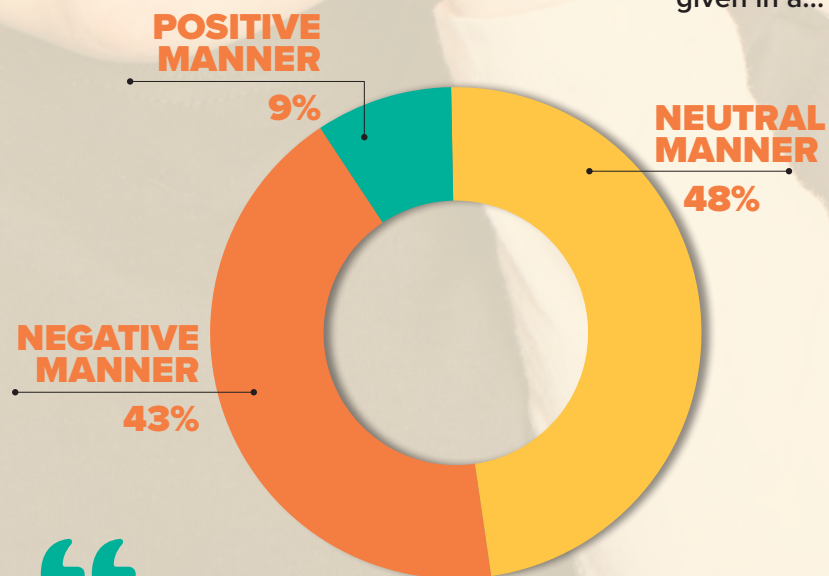


Sharing the news

Expectant and new parents are all too often being advised baby has Down syndrome in a negative manner, with those receiving the news whilst pregnant reporting an expectation to terminate.

When sharing the news around baby having Down syndrome, medical professionals have the power to make or break this situation; for parents to accept or reject their baby; to enable a parent to bond and love, or to be detached and distant.

Would you consider the high chance result was given in a...



We found out the day after baby was born he had Down syndrome and the way I was told was absolutely horrific: my partner was not present, I was on my own with my beautiful baby and was left feeling devastated with no one to talk to. My partner thought baby was dying because I phoned to tell him and I was so upset I couldn't get the words out



Consultant came around later with his students, introduced baby to them as a "suspected Down's baby". I hadn't been told at that point.



They said I didn't have to take her home, many don't, I'm only young, no reflection on me, life will be difficult for her, me and my son, she might never walk or talk, she'll never have a normal life, blah, blah, blah.



We were given a badly put together leaflet off the internet after a postnatal diagnosis, which included "What to do if you don't want your baby."



If only they realised that the words they use will stay with you forever!!



Sorry, we've got bad news" about an hour after she was born, putting me into a huge frenzy thinking she had something wrong with her like she was going to die or something.



SUPPORT

For many expectant parents discovering baby has Down syndrome will come as unexpected and potentially unwelcome news. At a time when mum is already feeling vulnerable and potentially anxious, support from a trained expert is critical.

On receiving the news baby has a high chance of having Down syndrome, two thirds of the expectant women **(66% of 144 respondents)** were never offered any counselling or form of support, and over half the expectant women left the hospital with no information about Down syndrome.

Given the prevailing presumption to terminate, most expectant parents are being expected to make life/death decisions without information or support.



When I arrived to discuss my options it became apparent to me that it had been assumed by medical professionals that I was there for further testing. I felt very rushed into deciding there and then what I wanted to do. This decision was expected to be made by me without any understanding of what having a child with Down syndrome would even mean for me and without any clarity of the situation at that time.



After my initial over-the-phone diagnosis, I kept waiting for someone to talk to me about Down syndrome and what it will mean, or give me a leaflet or something, but it never came. I felt there would have been more support if I was terminating my pregnancy.

INFORMATION

It is imperative that expectant and new parents are provided with accurate, contemporary information about Down syndrome. All too often, medical professionals overwhelm parents with lists of potential medical complications their baby may have. Parents crave an understanding of the reality of life with Down syndrome, the lived experience, and by signposting to local families, support groups and national organisations such as PADS, new and expectant parents can discover this reality.

However, the survey shows that most expectant parents, after being advised there's a high chance baby has Down syndrome, are sent home without relevant literature **(56% of 144 respondents.)**



Had high chance pregnancy but no info until, after two weeks of my son being in intensive care, I was given a tatty old leaflet from the matron who proceeded to tell me thankfully her daughter didn't have Down syndrome even though some had commented once she looked as if she did.



I asked for information, literature, leaflets, anything, but they didn't have anything in the whole hospital. They had to get some sent from another health board but only requested them after the blood results.



Going forward

This report corroborates concerns held by many within the Down syndrome community that parents expecting a baby with Down syndrome are being pressured into screening and encouraged to terminate. It highlights that many medical professionals have outdated negative views of Down syndrome, and we are of the view that these attitudes, combined with lack of support and information, undoubtedly contribute towards the high levels of terminations we have seen over recent years.

We want to work with all parties to address this unacceptable situation. We await the long overdue Guidelines from the RCOG for supporting women continuing a pregnancy. Meanwhile, an interim statement is due from the RCOG and RCM to 'ensure all clearly understand the importance of providing impartial support and options to women and their partners throughout antenatal screening through to diagnostic results and beyond.'

CULTURAL CHANGE

Working with medical professionals, we need to address the systemic discrimination by educating professionals about the reality of living with Down syndrome in the 21st century.

It is imperative that medical professionals understand that:

- ▶ It should never be assumed that a woman will choose to have a termination because her baby has a confirmed/ high chance result of having Down syndrome.
- ▶ Many women have screening in order to prepare, and do not have a decision to consider; indeed, they find it insulting and disrespectful for medical professionals to suggest they might wish to terminate.
- ▶ If a woman intimates she is considering her options, then they should be presented in a non-directive, non-judgemental and supportive approach: to continue, to have baby adopted, or to terminate.
- ▶ In all instances, including whether to screen or not, to continue a pregnancy or not, a woman's choice must be accepted and respected.
- ▶ Women must have access to contemporary information about the social model of living with Down syndrome:

www.positiveaboutdownsyndrome.co.uk





+ Proud to be a Positive about Down syndrome Champion



IMPLEMENTATION OF A DOWN SYNDROME CHARTER ACROSS MATERNITY UNITS

We have introduced a nationwide Down syndrome Charter to standardise information around Down syndrome, ensuring parents of a baby with Down syndrome are not subjected to discrimination but can enjoy a positive maternity experience.

Collaborating with local support groups, the Charter will create Positive about Down syndrome Champions.



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